

Doctors with Asperger's: The impact of a Diagnosis

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Abstract

Background: Asperger Syndrome (AS) is part of a spectrum of disorders encompassing difficulties with social interaction that may result in specific educational needs for doctors in training. There is currently limited research on the impact of AS on work as a doctor.

Methods: This is a qualitative study using semi-structured interviews to explore the perceptions of trainees diagnosed with AS following input from a professional support service and the staff involved in their professional development.

Results: Receiving a diagnosis of AS was viewed as a double-edged sword, allowing the development of insight into lifelong difficulties, but also creating the potential for prejudice.

Discussion: This study explores the benefits and disadvantages of defining and labelling a specific professional support need for a group of trainees. It also reveals the requirement for better awareness of AS amongst all clinical educators.

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Introduction

Asperger Syndrome (AS) is part of a spectrum of disorders that can result in difficulties with social interaction, present in around 1.1% of the UK adult population (1). It is not uncommon for AS to be identified later in life, as those affected can have high intelligence, with strong cognitive and verbal abilities (2) (3). These individuals often have traits that particularly lend themselves to becoming skilled medical practitioners, such as attention to detail, responsiveness to structure and unique perspectives for creativity. However, as with all trainees, they may experience times when they need additional support in training due to some traits, for example difficulties with peer relationships in the workplace.

Professional support units (PSU) have been developed to assist doctors in training who find themselves in need of support for a range of different professional and personal reasons. In the Wessex regional PSU we observed that some trainees referred were subsequently diagnosed with AS. These trainees needed specific additional input from the PSU to progress through their training, however there is a paucity of published literature on how best to support them.

In the general population, there is evidence to suggest that support in employment can reduce underemployment for people with autistic spectrum disorder (4) and evidence for the effectiveness of psychological intervention for adults with AS more specifically (2). However, there is little published research into the implications of the diagnosis for high achieving medical professionals.

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This article explores the impact of receiving a diagnosis of AS and the effect on developing insight into specific challenges in medical training.

Methods

We used a qualitative, case-study based methodology to explore the perceptions of trainees who had been diagnosed with AS through the Wessex regional PSU (5). The data were triangulated with experiences of the PSU staff. We used PSU records to identify all trainees with a formal diagnosis of AS known to the service, their case managers (CM) and staff providing specialist support. Specialist staff included a psychologist, occupational therapist, educationalist and psychiatrist. Participants were required to give full written consent prior to participating. Ethical approval for the study was given by the University of Winchester. This study is part of a wider project examining the support provided for these trainees and we intend to publish further details of the programme in subsequent work.

Semi-structured face-to-face interviews were conducted between February and May 2016. The interviews lasted between 30 and 70 minutes and each was audio-recorded and transcribed verbatim.

The data were coded and analysed thematically (6). A constant comparison approach was used, whereby codes from the interviews were categorised and compared to those identified in subsequent interviews. As new codes were generated, these were

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correlated with previous data and emerging concepts were connected to produce themes.

Results

All those invited agreed to participate in the study and the 10 interviewees included three trainees with a recent diagnosis of AS, three case managers and four specialists working with the PSU. All participants described the wide-ranging effects that the diagnosis had on the lives of these trainees, and this report focuses on the impact of receiving and sharing this diagnosis as a doctor. Emerging themes included: The diagnosis as a double-edged sword; developing insight into problems; and the effect of disclosing the diagnosis. These are explored further with supporting quotes in accompanying boxes.

A Double-edged sword

The diagnosis of Asperger syndrome was perceived to have a huge impact on these trainees, with an initial mix of reactions for each trainee. Overall it was perceived as a 'revelation', providing an explanation for years of difficulties, however it was also described as a double- edged sword (box 1). Whilst it allowed the trainee an understanding of many lifelong problems and challenges in their career for the first time, it was also perceived as a potential for stigma and prejudice. The trainees did not want to be treated differently because of a label, yet all participants described a lack of understanding about the significance of the diagnosis and negative misconceptions amongst educators.

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All the trainees were diagnosed in adulthood following referral to the PSU for additional support in training, and one specialist expressed concern about the effect of years of unexplained negative feedback. A sub-theme also emerged about the effect of receiving this diagnosis as doctors themselves, more used to diagnosing others, and the psychological adjustment this required.

Box 1: A Double-edged sword

"I don't know how to describe it - like a revelation moment ... that's what's been going on all my life – wow" (Trainee 1)

"I think there was ... an awareness that explained ... why things had not worked out as they should. I think it also had unfortunately a negative impact on the perception of other people on them, because they also experienced "Oh you probably can't do that." Almost disabling them because of the diagnosis, so it was ... a two-edged sword" (Specialist 1)

"I think the absolute most helpful [aspect], which [on] the flipside can be harmful, is the diagnosis in the first place... That just opened up a whole new awareness of why negative feedback was coming in; why things didn't work when it seemed to work for other people; why somebody felt very different to the rest of the world" (Case manager 3)

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Insight into problems

Participants commented that receiving a label was only helpful if improvements could be made as a result. All participants expressed that the diagnosis of AS allowed insight into the nature of problems and therefore a way to resolve them (box 2). Some participants described the perception of being 'blind' to the cause of issues pre-diagnosis. However, better understanding the Asperger traits provided a new perspective on difficulties in the workplace, for example challenges with social interactions or communication problems with supervisors. Working through these scenarios with PSU specialists then helped identify solutions, such as focus on small talk or social exchanges. In another example, an awareness of the tendency to become absorbed with one specific patient, helped with prioritising clinical tasks.

The benefit of this insight for educators was also discussed, facilitating focus on specific areas of feedback to help trainees. This affected not only the PSU team, who could identify appropriate support services, but importantly individual supervisors in the clinical setting. A theme also emerged that the diagnosis should not be used as an excuse for poor practice or failure to support a trainee, but an opportunity for education and development. All the trainees made it clear how important it was for them to work successfully as a doctor. There was no question about changing careers, and they were clearly passionate and determined about achieving success in their work.

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Box 2: Insight into problems

"It's a revelation and it just means that you have something to work with, once you've recognised it. The thing is most people with Asperger's don't know they have it, and they don't realise that these are documented traits, [they] think that's ... just me, but these are traits that have ramifications" (Trainee 1)

"I remember a couple of meetings, one in particular, extremely powerful meeting, where you could see the educators switching their attributions from 'this person doesn't want to cooperate with us, to this person's actually in a really difficult world and they're doing their best to manage it'" (Specialist 4)

"I don't want to use it as an excuse ... 'I was rude with them because I have Asperger's.' No, that's not the point" (Trainee 3)

Disclosing the diagnosis

Whilst disclosing the diagnosis could be helpful in improving communication and feedback in the workplace, the participants described very mixed responses to informing others (box 3). A fear of being treated differently may have prevented

trainees talking openly. They clearly found some reactions to the disclosure

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distressing, describing a widespread lack of understanding. All participants reported significant misconceptions about AS and sometimes associated stigma. Some very negative experiences were described, for example a supervisor was perceived to start collecting evidence about weaknesses, in an attempt to remove a trainee from the programme.

All participants discussed the need for improved awareness around AS and further education. It was suggested this could improve not only daily interactions and training for these individuals, but earlier detection for future trainees. A sub-theme emerged about whether the diagnosis represented a 'disability', with some commenting that it should not be viewed as such, but simply a different way of thinking. Several participants also highlighted the need to focus on the strengths of trainees with Asperger's and positive qualities they can bring to the team, including propensity for high intelligence and attention to detail.

Box 3: Disclosing the diagnosis

"I didn't want people to treat me differently. I had already been working at the hospital ... nearly two years and had good relationships with people. I didn't want them to suddenly feel like they couldn't talk to me ... They already knew me as slightly odd, I didn't need them to see me as any odder. People don't understand it"

(Trainee 2)

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"I think it's a huge problem. I think there's prejudice, I think there's misunderstanding, I think there's maybe a little bit of avoidance [as] they've got to work out a way to deal with somebody differently and ...[a] lack of awareness" (Case manager 3)

"What I'm ... very keen to stress when I talk to educators, is this isn't a one-sided process where someone has a 'disability' and you make reasonable adaptations because you have to, but actually you'd be better off without them there. Trainees with Asperger's have masses to offer to the medical profession; they're diligent, they're conscientious, their attention to detail is amazing, their memory tends to be brilliant. Obviously, I'm generalising but they've so much to offer" (Specialist 4)

Discussion

A limitation of the study is the small number of potential participants, however all those with a known diagnosis of AS were invited and all agreed to participate. In view of the small number of interviewees, further demographic details have not been published to protect anonymity. The study size also limits the extent to which findings can be generalised. Triangulation of data from both trainees and the different PSU staff working with them, allowed a wider exploration of the effect of diagnosis. This study design did lead to a larger proportion of staff interviewed, however emerging themes were similar in both groups.

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The findings in this study correspond with those in the limited published literature on the experiences of adults diagnosed with AS and those working in the healthcare sector (1) (3) (7). However, our study also explores the experiences of trainees and staff in obtaining specific insights into developmental needs through this diagnosis. Participants expressed a sensation of being 'blind' to the cause of problems prior to the diagnosis, and parallels can be drawn with this challenge in professional support in other literature (8). ~~Studies show that~~ It is common for poor performers to be simply unaware of their deficiencies and helping to establish this insight is a difficulty many clinical educators face. For the trainees in this study the diagnosis provided a moment of revelation, and they were observed to be highly motivated to improve once the reason for issues became apparent.

The findings of this study identify a paradox in the benefits of the diagnosis (insight and improved feedback), with the possibility of harm from prejudice and stigma. Disclosing sufficient information to obtain appropriate support appeared to be a complex balance. The difficulties in admitting to areas of weakness have also been explored in other literature. Links can be drawn with research on maintaining professional credibility (9). A fear of exposing weaknesses that could be construed as evidence of poor progress in training may prevent trainees from seeking help. For the trainees in this study this was exacerbated by the perception of widespread misunderstanding around AS.

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Conclusions

A unique programme of support has been developed for trainees with AS. This has allowed these trainees to gain insight into the cause of difficulties in medical training and enabled work on addressing these challenges. However, there was felt to be a widespread lack of understanding of AS amongst educators and supervisors. Further research is required to evaluate the sustainability and lasting effect of this professional support for doctors with AS. A better understanding of the implications of a diagnosis of AS will help to improve the support services for future trainees.

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Acknowledgements

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